Spiritual Beliefs and Response to Disability by Adults with Disabilities and Family Members

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As a nurse and parent of a young adult with physical disabilities, I was puzzled by people's different responses to disability: I observed that some appeared to have a bitter root (see Hebrews 12:15) that permeated their spirits, coloring their response to life, its meaning and their relationships. However, I observed others with serious limitations whose lives were filled with joy.

My questions surrounding people's differences in response to disability inspired qualitative research (Treloar, 1999a) that explored the relationship of the participants' spiritual beliefs, their response to disability, and the evangelical Christian church's influence on respondents' experiences. I used grounded theory methods (Glaser, 1978; Glaser, 1992) to code and analyze transcribed data from unstructured, conversational interviews with 30 participants.

Description of the Participants

The participants fell into two major groups: 13 parents of children with mixed developmental disabilities and 9 adults with physical disabilities. Eight family members provided additional data. Seven of the adults had disabilities at birth or early in life, while two developed adult-acquired disabilities. The parents ranged in age from 27 to 52 years. The adults with disabilities ranged in age from 22 to 84 years. Most of the parents and one-third of the adults with disabilities were married. Nearly all of the participants were white, with a high school or greater education. They lived in lower and middle economic neighborhoods in a southwestern metropolitan area in 1998.

The majority of the participants attended evangelical churches from a variety of denominational and nondenominational backgrounds. All of the parents and adults with disabilities ascribed to evangelical Christian beliefs: they shared a belief in the Bible as the inspired, inerrant, authoritative Word of God.

Significance of the Study

The study provides a unique look at the way evangelical Christians responded to lived experience with disability. In this study, adults with physical disabilities and family members used their spiritual beliefs as an interpretive frame to establish meaning for and as an adaptive resource for disability. The process of testing and trial, spiritual challenge, personal brokenness and reliance on God led to strengthening of faith and other benefits.

The study contributes to the growing body of knowledge that establishes a positive role for religious faith in experiences that affect well-being. Implications can be drawn for church leaders concerned about their theology and relationships with people affected by disabilities, and for professionals who provide holistic caregiving.

Context for Disability and Spirituality

Although nearly one in five persons, 54 million people in the United States (National Organization on Disability/Louis Harris & Associates, 1998) have a disabling condition that interferes with major life activities, we commonly think that disability happens to the other person.

Despite a contemporary socio-political definition for disability that views difference as normative (Nagler, 1993), disability typically conjures up conflicts between weakness and strength, dependency and independence, difficulty and heroism.

Negative attitudes toward the population and theological confusion for disability have historical and cultural origins traced to ancient civilizations (Barnes, 1996). Many people in biblical times viewed those with disabilities as sinful, demon-possessed, separate from the rest of humanity, and unclean. In ancient Greek and Roman cultures, babies who were sickly, weak, or born with physical disabilities commonly were killed, or left to die. Language and

attitudes surrounding disability reveal centuries old beliefs involving stereotype, stigma, and devaluation.

Unfortunately, these influences continue to affect our perceptions surrounding disability. Gourgey (1994) observes that people within the church, similar to those outside of the church, commonly see people with disabilities as a "separate and perhaps unreachable group." Creamer (1995) writes that most Christians do not intend to harm people with disabilities, good intentions are intended. Yet, the church similar to the public may relate to people with disabilities as those who are different, not the same as others.

Despite theological and socio-cultural obstacles, there are more positive than negative functions of religiousness in families with disabled members (Rogers-Dulan & Blacher, 1995). Religious belief systems, apart from formalized religious practice, may promote acceptance and provide a way for families to give meaning to the disability (Bennett, Deluca, & Allen, 1995; Paterson, 1975b; Wrigley & LaGory, 1994). Yet contrary to positive findings, parents may experience increased stress associated with religion, including perception of religious failure or punishment for wrongdoing. In some cases, parents turn away from religion (Weisner, Beizer, & Stolze, 1991).

Because we are thinking, feeling, spiritual beings, we seek to understand the reason and purpose for disability. Our questions include the following: Who am I and what does disability mean for my life? Why me? Why now? What did I do to deserve this? How can a good God allow this? Did God cause this? Why doesn't God heal me (or my child): Do I lack faith?

While most religious traditions address suffering, those who seek theological explanations for disability will seldom find a clearly articulated single answer (Paterson, 1975a). The problem becomes magnified when churches fail to provide clear or adequate teaching from a biblical perspective (Blair & Davidson, 1993; Blair, 1994; Eiesland, 1994; Gourgey, 1993). In the midst of theological confusion and public attitudes surrounding the meaning of disability, people with disabilities may internalize negative messages; the outcome is rejection of God and spiritual beliefs that could be helpful (Gourgey, 1994).

Like Western medicine with its acute care focus, the church often fails to provide long term spiritual support and care for people and their families with disabilities or chronic illness (Blair, 1994; Sutherland, 1993; Vanderzee, 1993). Although religious organizations are exempt from the Americans with Disabilities Act (except for the employment and promotion provisions in Title One), there is an ethical obligation to remove barriers that prohibit the equal participation of any person, disabled or nondisabled, in the church.

Findings for the Study

The spiritual meaning of disability cannot be separated from other aspects of lived experience. Factors that affected the participants' interpretation of disability and accompanying faith responses included: spiritual beliefs, theological grounding in biblical scriptures with life application (established faith), practical/social support, developmental stage in life (psychosocial and spiritual), and sociocultural, familial and other factors. One family's situation illustrates these factors. Peter explained that his prior religious education prepared him for an event such as the birth of his daughter, Michelle with spina bifida and hydrocephalus. Peter says:

> It's not a credit to the strength of my faith that we didn't go through an agonizing, "Why has this happened?" or questioned whether God is good. There wasn't a time of that because He's been preparing me for this situation. I had a very godly upbringing. I had been exposed to God and who God is, for the longest time.

Peter's ability to apply biblical principles to experience influenced spiritual challenge associated with establishing meaning for disability. Peter's developmental stage in life suggested a high level of psychosocial and spiritual maturity for response to life's stresses. In addition, both he and his wife felt extremely supported by people in their church.

Several religious factors positively influenced the participants' response to chal-

lenges associated with disability. Participants reported a high level of intrinsic religious spirituality with a biblical theological foundation for their beliefs: God was at the center of their ultimate concerns. They used biblical scriptures and their faith to provide meaning for their lives. They noted decreased spiritual distress for disability when their life circumstances were congruent with their spiritual beliefs. While high religious support by the church promoted positive adaptation to disability, it was not as important as the participants' personal relationship with Jesus Christ.

The participants' spiritual beliefs and life experiences were interwoven with disability. They experienced God in ordinary and extraordinary events of life. Analysis of the data reveals a basic social process in which a maturing faith and a deepening personal relationship with Jesus Christ followed ongoing testing and trial and associated spiritual challenge leading to personal brokenness and reliance on God. Testing and trials common to lived experience with disability contributed to spiritual challenge. Spiritual challenge included a search for the meaning of events related to disability. Participants reported questions concerning the relationship of disability to sin, the judgment of God, adequacy of faith, and miraculous healing. Repeated questioning of God, drawing nearer to God and rarely, walking away from God for a limited period of time are examples of a range and severity of responses that accompanied spiritual challenge. Consistent with this, both groups of participants occasionally reported personal, familial, and societal blame. Parents more frequently reported blame than did adults with disabilities. The following excerpts from the data illustrate spiritual challenge associated with the process for building of faith.

Theresa, single mother of a 5 year old son with profound intellectual and physical disabilities, remarked:

> What I've been through has made me stronger. Now I thank God for my boy. But when he was born, I thought God was punishing me. I couldn't believe it! I really had a rough time. I didn't understand how God could give me a problem like this, when I had so many problems to begin with.

Cathy and Barry, adults with developmental physical disabilities, observed that many people blame God for disability at some point. Megan said that occasionally the public asks if she is angry with God for her daughter Michelle's spina bifida. The central questions in her report involve disability as punishment and issues surrounding the goodness of God (theodicy). Her comments reflect her theological background and a mature faith in God. Megan says:

> One person said to me, "Don't you hate God if He would do this to you? That He chose you to have a child with a disability?" Very strong words. Why, who am I? I don't have a right to say to God, "Who are you to do that to me?" I'm His child, so is Michelle. He's doing what He sees best for us, even though we don't necessarily see the big picture. Most of us have a limited perspective of who we are in relation to God, even people that go to church regularly.
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> Many question why a good god would do this. What possibly could God's reasons be? I know He's molding my character to be more Christ-like. I know He's allowing trials in my life so I can help others in similar circumstances. And I know He loves me. I only have a glimpse of what His reasons are. I don't need to know them all.

Paul, a young adult with physical disabilities secondary to neuromuscular disease, illustrates the process for development of faith and a deepening personal relationship with Jesus Christ. Paul says:

> A lot of people come up to me and ask, "Do you think the reason that God uses you so much is because you are disabled, you have time to sit around

and listen?" I kept thinking and thinking. I was reading in Psalms the other day that a good shepherd will break the leg of a sheep that goes astray. Not so much that I went astray, but if anybody knows anything about raising sheep, the reason the Good Shepherd does that is because when the sheep's leg is wounded, the sheep is actually carried around the shepherd's neck. The other scripture says, "my sheep know my voice and they will follow." That sheep went astray, why? Because it didn't know the voice of the master. Also, it wouldn't stay with the other sheep. So what it does is spend a lot of time, not only getting to know the voice of the master, but it's so close to him, around his neck that it literally knows the heartbeat of the master.

I'm one of those sheep that's been broken. I've gotten to spend a lot of time around His neck. It's easy for me to understand and to hear His voice. Where all those other ones that have been whole their entire lives have gotten out around the edges of the flock. When He speaks, they may hear it, but it's not as clear or precise. They certainly don't have the heartbeat.

Paul describes himself as having been broken; both he and the lamb can hear the shepherd's (Jesus') heartbeat as they are carried around his neck. Paul's mother, Mary, likewise speaks of "knowing" Jesus in a deep and intimate way that probably few understand in the absence of great trial and adversity. Being broken accompanied reliance on God and increasing faith.

What the participants' believed influenced how they lived. Outlook on life did not wholly depend on one's faith perspective. However, the participants chose to live with joy and thankfulness in response to stresses associated with disability. This reflected their belief in God's greater purpose and plan for their lives. John, a young adult with cerebral palsy, says:

My faith has to do with filling me with joy. If I'm filled with joy, and I think of joyous things, I don't think about the things that would make me embittered. So, therefore, I am not embittered regardless of what my physical limitations are. I guarantee you my physical limitations are many.... I know that there are people who have disabilities, who at least outwardly are some of the happiest people I've ever met. I guarantee you, they have never had anything to do with church and probably never will. But for me, I need to have faith and my disability together.

One of the main things my faith has done, quite honestly, it's kept me alive. It can be very frustrating because there's not a lot of people who really understand what disabilities are about. If I didn't have my faith, I'd be dead. Because of the tribulations that come with having disability; dealing with personal care attendants on a daily basis and the funding for getting that done and case managers for the state and various things like that. I couldn't handle it!...Without something to go to, without one stable thing to hold onto, I don't think I would have made it. By this point, if I didn't have the faith that I have, I probably would have committed suicide. I think that there's not a whole lot to understand about that. I'm very physically dependent on somebody else. Somebody decides not to show up. And I'm sitting in a chair all night or whatever until I can find somebody.

Faith in God for both adults with disabilities and parents facilitated effective coping in response to difficulties. Although several parents and two adults with disabilities expressed themes of chronic mourning, this did not consume their focus.

Both adults with disabilities and parents saw the church as an important social institution that facilitated acquisition and growth of their spiritual beliefs. All participants agreed that the contemporary church depends on its leaders to guide the congregation to reach out to

people with disabilities. Inclusion into the church extends beyond physical and sensory accessibility. The participants emphasized attitudinal accessibility: a mental and emotional readiness to minister to and with people affected by disability. Although they recognized that disability might contribute to fear and avoidance by those who do not share their experience, they believed the solution requires serving one another. However, while people with disabilities have gifts to share with others, they may be viewed as a burden or a drain on limited personal and instrumental resources.

Several participants verbalized awareness that people with disabilities are greatly under represented in churches. They stated that reasons for this include faulty assumptions about the needs and gifts of people affected by disability, lack of knowledge of disability by others, discomfort with disabilities, and avoidance by church staff. Other reasons included excessive caregiving stresses by families and churches unprepared to integrate the population into the congregation. Other perceived risks for churches included loss of able-bodied members and financial constraints with creating physical accessibility.

The participants' recommendations for the church fell into two categories: efforts to promote theological understanding of the meaning of the experience of disability and practical support. The participants believed that ministry that includes long term and continuing needs should complement a short-term, crisis-oriented model.

Lack of a biblical foundation for achieving meaning in disability promoted spiritual distress and movement away from God and the church for a few participants. The participants emphasized the need for increased assistance by the church in establishing theological meaning for disability. Only two participants recalled a pastoral lesson related to disability. One mother, Connie, said: "I would to have liked to have had somebody tell me, instead of me having to read that my child is the way he is, because God did it or allowed it." In the absence of assistance by pastoral leaders, Connie found help through reading a practical Christian text (Dobson, 1993).

Barry, whose comments reflect his experience as a counselor and a person with physical disabilities, explained: "Any time you have a disabled problem, I think you're going to wonder, 'Did I do something wrong? My father was that way.'" Bill, a parent who regularly attended small rural Protestant churches and a large Bible-based church for 40 years, expresses his frustration:

> What does the Bible say about disabled [persons]? Right at this point I assume there isn't anything, because I've never heard anything....Are there any references? I don't know. I would assume no. See, that makes it very difficult even for Christians to rectify that and to justify disability within their minds. If the pulpit never says anything about disabled [persons] then my thought process is that Jesus never addressed the issue. I know he healed the disabled. Don't get me wrong there. But how does Jesus hear them? Are they special; are they different?

Bill stated that his lack of a biblical foundation for understanding of disability allowed Satan to tempt him years earlier with thoughts that God was punishing him through failure of miraculous healing for his daughter, Cathy. He believes that pastoral teaching on disability would provide a biblical foundation for understanding why God does not always heal, and help to alleviate spiritual distress and turning away from God.

Kevin, a former clergy, said that issues surrounding people with disabilities in the church are "totally missed" for a combination of reasons. Kevin compared this situation to avoidance of persons who are dying. He explains:

> The whole area is missed, probably for a combination of reasons. I picture it much like the grief process and somebody is dying. Everybody assumes the dying person doesn't want to talk about it. The dying person assumes the other people don't want to talk about it. So they don't talk about it. Then there's lack of knowledge about it.

Despite complaints about theological confusion on topics including the relationship of disability to sin, adequacy of faith, and miraculous healing, the participants' spiritual beliefs provided meaning for their experiences. However, the data suggest that an inadequate scriptural foundation related to disability impedes positive adaptation to associated spiritual challenges. In view of this, church leaders should evaluate historical positions that have been assumed without clearly studying theological issues surrounding disability. Churches must openly and directly address disability and accompanying theological issues from a scriptural perspective so that church leaders and congregations alike have a theological basis for establishing meaning related to disability.

The participants' recommendations for religious support emphasized the theme that people with disabilities have needs and gifts that are common to others, yet unique (they are the same, but different). Practical (instrumental) support issues were more likely to be discussed by parents than by adults with disabilities. Several participants believed that special ministry considerations for people affected by disability are warranted. Marg explains:

> I think the greatest need, if I was telling churches what to do, would have been for them to have come to me and to ask me, "What can I do to help you?" And secondly, to offer to take Beth sometimes, so that the rest of our family could have done things together that we were hindered in doing. Playing games, just normal games, for instance, that we had to lay down. (tearful) Time for Ted and I. It made us work at asking for help with Beth, which is hard.
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> It's hard to ask. The first and second time you feel like maybe people won't mind. But the fifth year, and the twelfth year, and the fourteenth year, I hesitated and felt like people started avoiding me for fear they'll have to help or that my presence makes people feel guilty. I felt people back away from me. A child grows up. You get baby sitters for a short while. But with a child with disabilities, you still need the relief. You still need the help.

Marg's data raises the need for respite care; and it highlights the importance of addressing the population's needs from a continuing ministry model. In summary, the participants recommended that the church assist people affected by disability to establish theological meaning for disability and provide practical support that allows their equal participation in the spiritual life of the church.

Methodological Considerations and Limitations

I used an exploratory qualitative research design for data collection and analysis because of the rich detail in examining meaning through one's experience. Neither objective tools nor multiple measures were incorporated into the design. The nature of the interview experience, the participants' response to me, and their expectations may have influenced their responses. Comparison of the population to others who do not hold similar religious and spiritual beliefs may provide increased insight into the influence of the participants' beliefs on response to disability. Participants from diverse cultural backgrounds and additional family units may produce variation in findings.

Regardless of whether the participants' narratives included problems with memory, exaggeration, or confusion, they represent the "truths" of their experience (Riessman, 1993). The family and parent couple interviews were an advantage rather than a limitation. Family members stimulated others' memories, leading to comparison of experiences. The fact that this did not provoke family discord speaks to harmonious family structures and well-developed communication skills among family participants. One adult with disabilities chose not to be interviewed with his mother because he wanted me to hear how his mother viewed his disability: He was aware of the divergence of their views.

To increase the validity of my interpretation, I constructed participants' portraits or depictions that combined interview excerpts with themes from the data (Douglass &

Moustakas, 1985; Moustakas, 1990). A portrait can be compared with the use of excerpt files that the researcher constructs from full interviews for the purpose of coding (Weiss, 1994). Participants reviewed their portraits, conversation was stimulated and written changes were made. This provided opportunity to validate that I had understood the participant's experience to the extent that this can be accomplished.

Analysis of the data occurred concurrent with data collection (Lofland & Lofland, 1984) consistent with grounded theory methods (Glaser, 1978; Glaser, 1992). I analyzed the parents' data first, followed by that for the adults with disabilities. Finally, I considered data from the family units. By the time I completed coding of the parents' data, no additional categories and few additional coded words were identified.

Regardless of construction of the participants' portraits, use of thick description to report the findings, and documentation of my decisions in a methodological log, some may charge that my shared experience with disability influences my interpretation and analysis of the data. No doubt that is true. Denzin (1989) says, "Value-free interpretive research is impossible because every researcher brings preconceptions and interpretations to the problem being studied" (p. 230).

All participants received a summary of the findings. One participant remarked that she could "find herself" in the visual diagrams which accompanied the findings. The participants' data illustrate remarkably consistent themes, providing internal consistency. I suggest that readers having a shared religious perspective will find that the outcomes are plausible.

Final Comments

This study and the literature continue to build support for the recognition of spiritual beliefs as a stabilizing force for people with disabilities and their families. What the participants' believed influenced how they lived: their spiritual beliefs provided assistance with coping and multiple benefits for the experience of disability. The study provides a unique look at the way Christians with biblically-based beliefs responded to lived experience with disability. A maturing faith and a deepening personal relationship with Jesus Christ followed ongoing testing and trial and associated spiritual challenge leading to personal brokenness and reliance on God. Applications from the data can be drawn for church leaders and congregations, seminaries that prepare them to do their work, and professionals with family science and health-related backgrounds.

Holistic caregiving establishes an environment that promotes recognition and achievement of spiritual needs surrounding disability (Treloar, 1999b). Professionals should incorporate key questions in their assessments and use other strategies that invite communication about spiritual needs and concerns. Receptivity to others' spiritual needs requires comfort with personal spirituality. In talking directly with the person/family about these issues, providers must not push their version of spirituality. Professionals can collaborate with pastoral staff and qualified counselors to help individuals and families grapple with spiritual issues surrounding disability. Their resource network may include churches that have demonstrated acceptance and support of people with disabilities and others perceived to be different.

Professionals and other service providers can encourage their religious institutions to openly address disability and accompanying issues so that church leaders and congregations alike have a theological basis for establishing meaning related to disability. Establishing meaning for disability and reconciliation of blame for a child with disabilities appear essential to family and marital harmony. Early intervention efforts in families affected by disability should include all members, including fathers and siblings.

Families commonly complain about exhaustion through battling to survive disability concerns during the week. If life's skirmishes continue at the local church - if churches don't practice attitudinal, physical, and sensory accessibility - families won't risk involvement in churches. Spiritual involvement will be shoved to the bottom of the family's priority list. Webb-Mitchell (1994) writes:

> Until our church buildings, worship, and Christian religious education programs are made inviting, accessible, and open to all who wish to enter and

join in the life of a church, there is little chance that people with disabilities will be seen or heard from there. They will remain outside of the building, rejected from potluck affairs, excluded from worship, and left out of the religious education activities and pastoral ministry of our congregations. They will be more angry and bitter than ever. (p. 101)

Webb-Mitchell's last statement returns to my life-long question about why some people with disabilities are angry and bitter toward life, while others respond with joy and resilience despite overwhelming difficulties. I suspect that the church doesn't like to consider that its actions may contribute to these attitudes by people affected by disability.

Stiteler (Thornburgh, 1996) writes, "Two main images found in most religious writings reinforce negative attitudes toward people with disabilities: disability as punishment for sin; people with disabilities as objects of charity" (p. 8). Interpretation of disability as blemish or imperfection neither reflects God's design, nor today's socio-political definition for disability. The remedy resides in manipulation of the environment, rather than in correction of the individual. The church's challenge is to remedy barriers to inclusion of any person, disabled or non-disabled, into the community of God. Full inclusion of the population into religious community meets a Christian ethical imperative with positive outcomes for both the congregation and people affected by disabilities.

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